

Building and Delivering a Successful Dementia Research Portfolio through Collaboration

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1) Why Collaborate?

- It is estimated that over 13,000 people within Devon have a diagnosis of dementia, which is predicted to rise to over 23,00 by 2030. These rates are significantly higher than the regional average across the majority of the UK, highlighting the demand for neurodegenerative research within the region. (Prince et al, 2014)
- It is a primary aim of the NIHR to increase the opportunities for patients and the public to participate in, and benefit from, research. Furthermore the Prime Ministers 2012 Challenge on Dementia has given increased impetus to focus on dementia research.
- However within regions of Devon there has been limited opportunity to participate in dementia research. This is reflected in parts of the UK, often due to a lack of staffing and specific experience required to address the multidisciplinary methodologies of neurodegenerative studies.
- Royal Devon and Exeter NHS Foundation Trust (RD&E) and Devon Partnership NHS Trust (DPT), individually did not have the breadth of clinical skills and cognitive rating experience to secure complex commercial dementia studies. Therefore developing a synergistic collaborative research relationship was identified as a priority to address this issue. The Devon Dementia Collaboration (DDC) was initially devised by senior clinicians in DPT and RD&E and advocated by Dr Ray Sheridan, NIHR Clinical Research Lead.

3) Challenges and Solutions faced

- **Collaboration results in:**
 - Easier, faster and more coherent access to services,
 - a greater effect on systems, and increased creative problem solving
- **Clinical research collaboration results in:**
 - Positive outcomes in recruiting & retaining participants/carers for studies. Indirect benefits to the growth and development of the research team (Bozeman and Boardman, 2014).

2) Building the Devon Dementia Collaboration



4) Progress to date - Summary

Research Work

Since the implementation of DDC, the team has:

- Secured both academic and commercial trials based upon mutual recruitment goals and the enhanced skill set of the combined staff.
- Set up a complex commercial study, the TOMMORROW study. Provided information to 750+ people, screening 204, then recruiting 32 to the study to date.
- Recruited for the IDEAL study since August 2014, starting our academic portfolio and meeting with patients and support groups across the community.
- Developed and improved their clinical and rating experience. Through increased access to training opportunities and peer supervision
- Ensured increased access to facilities, such as the Clinical Research Facility.
- Made a deliberate effort to develop a balanced portfolio, including academic research. This will enable us to undertake future commercial studies that require complex psychological rating scales, such as the Clinical Dementia Rating scale and the Clinical Global Impression of Change.
- Established a skilled team of clinicians
- Significantly increased the number of Expressions of Interest from commercial and academic studies with complex methodologies and in diverse fields of dementia.

Promotion and Development

The DDC has already been well represented at a regional PPI event for people with Dementia. Research staff gave presentations and contributed to an expert panel for discussion on issues raised by patients and carers.

A local workshop was also delivered by DDC staff which was well attended by trust leads throughout the peninsula, developing good practice.

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Challenges

Allocation of recruitment accruals

Financial arrangements

Integration of teams

Communication and coordination between sites

Inexperience in specific cognitive rating scales for commercial studies

Solutions

Determine study specific agreements on recruitment

Individual studies examined and arrangements agreed upon by team leads based on workload

Honorary contracts issued, regular team meetings and integration of IT systems

Identification of study specific coordinator and agreed methods of communication.

Shadowing, clinical and peer supervision. Focus on developing a balanced study portfolio.

Outcomes

Shift in focus from proving accruals to providing quality research.

Fair distribution of income

DDC team has now developed its own sense of unity and team cohesion.

Increased organisation and effective study planning and communication

Increased skillset development in staff members



References

Bozeman, B., Boardman, C.. (2014). Assessing Research Collaboration Studies: A Framework for Analysis. In: Research Collaboration and Team Science . Ohio: Springer International Publishing. 1-11.

Prince, M., Knapp, M., Guerchet, M. Prina, P., Comas-Herrera, A., Wittenberg, R., (2014). Dementia UK update: Second edition. 2nd ed. London: Alzheimers Society. pp.16.